

# Elderly patients also have rights

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**Background:** Sharing information with relatives of elderly patients in primary care and in hospital has to fit into the complex set of obligations, justifications and pressures concerning the provision of information, and the results of some studies point to the need for further empirical studies exploring issues of patient autonomy, privacy and informed consent in the day-to-day care of older people.

**Objectives:** To know the frequency with which "capable" patients over 65 years of age receive information when admitted to hospital, the information offered to the families concerned, the person who gives consent for medical intervention, and the degree of satisfaction with the information received and the healthcare provided.

**Method:** A descriptive questionnaire given to 200 patients and 200 relatives during the patients' stay in hospital.

**Results:** Only 5% of patients confirmed that they had been asked whether information could be given to their relatives. A significantly higher proportion of relatives received information on the successive stages of the care offered than did patients themselves. As the age of the patients increased, so the number who were given information, understood the information and were asked for their consent for complementary tests decreased. The degree of satisfaction with the information offered was high for both patients and relatives (86.5% and 84%, respectively), despite the irregularities observed.

**Conclusions:** The capacity of elderly patients to participate in the decision-making process is frequently doubted simply because they have reached a certain age and it is thought that relatives should act as their representatives. In Spain, the opinion of the family and doctors appears to play a larger role in making decisions than does the concept of patient autonomy.

Patients' rights to informed consent and confidentiality have transformed the relationship between doctor and patient.<sup>1</sup> The legislation of most countries recognises that patients have the right to receive whatever information is available concerning their health. Indeed, information is the basis of the patient–doctor relationship, and its provision is a precondition for giving consent before any medical or surgical treatment is undertaken.

A recent law in Spain (Law No. 41/2002) concerned with patients' rights and doctors' obligations in matters of clinical information and documentation clearly specifies that the owner of such information is the patient. However, the law also states that people associated with the patient, whether by family ties or more informal ones, may also be informed, but only to the extent that the patient wishes.<sup>2</sup>

In Spain, patients reaching 16 years of age are deemed competent, unless it can be proved otherwise, to participate in the decision-making process regarding the healthcare process. The law also establishes that clinical information must be provided in a comprehensible form suited to the patient's power of understanding.

Ethicists agree that informed consent is a process rather than just simply the signing of a form. It should provide the patient with the information and understanding needed to authorise a procedure. Essential elements of informed consent include a description of the procedure, the potential risks and possible benefits.<sup>3</sup>

The gradual ageing of the world's population and the high incidence of chronic disease are having a great effect on many areas of the healthcare system. The elderly constitute a group of potential patients who will increasingly need attention suited to their condition. Sharing information with family members of these patients in primary care and in hospital has to fit into the complex set of obligations, justifications and pressures concerning the provision of information,<sup>4</sup> and the results of some studies

point to the need for further empirical studies exploring issues of patient autonomy, privacy and informed consent in the day-to-day care of older people.<sup>5</sup>

The aims of this study are to determine the frequency with which "capable" patients over 65 years of age receive information when admitted to hospital, the information offered to the families concerned, the person or persons who give consent for medical intervention and the degree of satisfaction concerning the information received and the healthcare provided.

## METHODS

### Type of study

We conducted a cross-sectional survey, which was approved by the ethical research committee of the hospital in question.

### Study population

The study was carried out at University Hospital "Morales Meseguer", an urban-located teaching hospital in Murcia (south-eastern Spain), with a capacity of 340 beds and admitting an average of 638 patients aged 65 and over per month. The patients for this study were chosen by stratified random sampling, taking as sample population all the admitted patients aged 65 and older and making a proportional selection of beds from the various medical and surgical services.

The cognitive state of the patients was evaluated using the Short Portable Mental Status Questionnaire (SPMSQ),<sup>6</sup> excluding those patients with advanced cognitive deficiency (score of 5 or above) that would interfere with carrying out the test. Using this test, 200 patients were selected, excluding 21 who showed advanced cognitive deficiency.

### Data collection

The data were obtained by mean of a questionnaire given to 200 patients and 200 family members or accompanying persons

(henceforth called relatives) during the patients' stay in hospital (1 February–31 July 2005).

The objectives of the research were explained to patients and their relatives before asking for their consent to proceed with the interview, which was carried out separately for patient and relative.

The questionnaire covered the following variables: (1) Sociodemographic: sex, age, marital status, level of studies and relationship between patient and accompanying relative. (2) What is the diagnosis of the medical condition? (patient); what is the diagnosis of the patient? (relative). (3) Have you received information concerning the different phases of the care process: diagnosis, complementary tests, progress and treatment of the illness? (4) Was the information provided (a) in easily understood terms, or (b) in a medical language that you could not understand? (5) The information provided (a) increased your anxiety, or (b) decreased your anxiety (helped you relax). (6) Were you asked to give consent for complementary tests? (7) How satisfied are you with the information received (scored 1–3 on a Likert scale): (1, unsatisfied, to 3, satisfied). (8) What do you think of the quality of the care provided (scored from 1, very bad, to 5, very good)?

### Statistical analysis

The SPSS 12.0 package (SPSS, Chicago, Illinois, USA) was used for the statistical analysis of the data using simple frequency distributions, association between variables (Pearson's  $\chi^2$  test) and the Kruskal–Wallis test to compare groups.

## RESULTS

### Sociodemographic characteristics of patients and relatives

The sociodemographic characteristics of the patients and relatives are summarised in table 1.

**Table 1** Sociodemographic characteristics of the patients and relatives questioned

Characteristic	Patients,* No (%)	Relatives,* No (%)
Sex (male)	109 (54.5)	65 (32.5)
Age (years), mean (range)	74 (65–102)	55 (17–85)
65–70	73 (36.5)	–
71–75	49 (24.5)	–
76–80	47 (23.5)	–
81–85	21 (10.5)	–
>85	10 (5)	–
17–30	–	13 (6.5)
31–50	–	73 (36.5)
51–65	–	44 (22)
>65	–	70 (35)
Education		
No studies	183 (91.5)	103 (51.5)
Primary	4 (2)	33 (16.5)
Secondary	7 (3.5)	49 (19.5)
University	6 (3)	15 (7.5)
Marital status		
Married	141 (70.5)	–
Single	9 (4.5)	–
Widowed	48 (24)	–
Divorced	2 (1)	–
Relation to the patient		
Wife or husband	–	85 (42.5)
Son or daughter	–	82 (41)
Nephew or niece	–	7 (3.5)
Grandson or granddaughter	–	11 (5.5)
Brother or sister	–	2 (1)
Other	–	13 (6.5)

–, Not applicable.

\*n = 200.

### Information provided to patients and relatives about various stages of the care process

Only 5% of the patients confirmed that they had been asked if information could be given to their relatives. A significantly higher proportion of relatives than of patients received information about the successive stages of the care offered.

During the interview, 28% of the patients said that they did not know their diagnosis; by comparing the replies with the patients' medical records, we estimated that an additional 9.5% were also unaware of their diagnosis, bringing the total to 37.5%. Of the patients who did know the diagnosis (62.5%), 88.8% said that the information had been given in an understandable way, although 32.3% had doubts that they had not communicated to the doctor. As regards the effect that that information had on the patients' state of mind, 68% were less worried than before and 32% were more worried.

Within the group of patients who did not know their diagnosis, 75% had not been informed by their doctor, although in 33% of cases information had been given to a relative. In 35.5% of cases, patients had not been informed about the complementary tests that had been carried out. Although such tests were carried out in 100% of cases (and invasive procedures in 25%), 50.5% of patients had not been asked for their consent (whether oral or written). Consent was oral in 24.5% of cases and written in 25%. As regards the prescribed treatment, only 53% of patients were informed.

In 93% of cases, the relative knew the diagnosis—a figure that coincides with that for the clinical history. A similar percentage (94.5) claimed to have understood the information provided by the doctors about the reasons for admission. Of the relatives, 61.7% affirmed that the information made them less concerned and 91.7%, that the information was easily understood.

Of the relatives, 83% received information about all complementary tests and 77% had been asked for their consent (52% oral and 25% written) (table 2).

There was an inverse correlation between the information provided at the various stages and the age of the patients. As their age increased, so the numbers who were given information, who understood it and who were asked for their consent for complementary tests decreased (table 3).

### Degree of satisfaction with the information received and evaluation of care offered

The degree of satisfaction with the information offered was as follows for patients and relatives, respectively: unsatisfied (6% and 7.5%); neither satisfied nor dissatisfied (7.5% and 8.5%); satisfied (86.5% and 84%). No significant differences were observed between the patients' and relatives' overall evaluation of the care received views, which were mainly positive (fig 1).

Analysis of the replies that evaluated the quality of the care received as being "very good" (5 on a Likert scale) showed significant differences within the groups patients and relatives: those who had received information about the various stages of treatment and who had been asked to give their informed consent were those who had the highest opinions (table 4).

## DISCUSSION

Giving information to patients concerning their health status and the possible diagnostic and therapeutic procedures, including the expected advantages and potential risks, is an essential element in the patient–physician relationship.<sup>7</sup> However, our study showed that 72% of patients had received information on the progress of the illness, and only 53% had received information on the treatment itself. We also found that in all the stages of the process that required the patient to receive prior information from the doctor, more relatives than

**Table 2** Information given to patients and relatives during the healthcare process and regarding requests for consent to carry out complementary tests

Subject of the information given	Patients, No (%)	Relatives, No (%)	Probability*
Diagnosis	125 (62.5)	186 (93)	<0.001
Complementary tests	129 (64.5)	166 (83)	<0.001
Progress of illness	144 (72)	165 (82.5)	0.008
Treatment	106 (53)	126 (63)	<0.001
Informed consent requested for complementary tests	99 (49.5)	154 (77)	<0.001

\*Pearson's  $\chi^2$  test

patients were given the information. Furthermore, in only half of the cases was the patient's consent sought before complementary tests were performed, even though all the patients in the sample fulfilled the requirements under Spanish law to be informed.

This situation suggests that the capacity of elderly patients to participate in decision-making is frequently doubted simply because they have reached a certain age<sup>8</sup> and it is assumed that family members should act as their representatives. As in other parts of the world, it seems that preserving community norms and family relationships is more important than individual autonomy.<sup>9</sup>

The problem of deciding whether a patient is in a condition to take decisions is one of the most difficult when obtaining informed consent, and it is generally the doctor who judges the capacity of an individual to understand. The assessment of capacity to consent to a healthcare decision is an important part of day-to-day work in general hospitals, but it has not been fully studied in Spanish practice. The paternalistic attitude of healthcare professionals, although a diminishing problem, still reigns in some situations, particularly, it seems, when it comes to caring for the elderly. While the social framework of decision-making has diminished in significance and Western bioethics now focuses more on ethical decisions that are based on individual autonomy,<sup>10</sup> our findings indicate that this situation is more theoretical than real.

Another problem that takes on great importance is the role of the family within the triangular relationship of doctor-patient-family. Our findings suggest that the flow of information is towards the family, especially as regards diagnosis, since only 62.5% of patients knew this, in comparison with 93% of relatives. In addition, only 5% of patients were asked if family members should be informed. In a previous survey of primary care doctors, we found that 95% disclosed information to patients' families and that only 35% thought it necessary to obtain the patient's consent before doing so.<sup>2</sup> We now see that in the case of elderly patients, consent is even less likely to be sought.

In Spain, as in many other countries, a person has a right to choose whether to consent to medical treatment, whether the

reasons for making that choice are rational, irrational, unknown or even non-existent. The decision-making competency of a patient is attested to by the presence of abilities, the expression of willingness, an understanding of the treatment to be offered and its consequences on life and health, and the full ability to evaluate alternatives; furthermore, the patient must be seen not to be acting under the strain of anxiety or nervousness. Older people have the same rights to self-determination as younger people<sup>11</sup> but not always the same capacity for understanding.

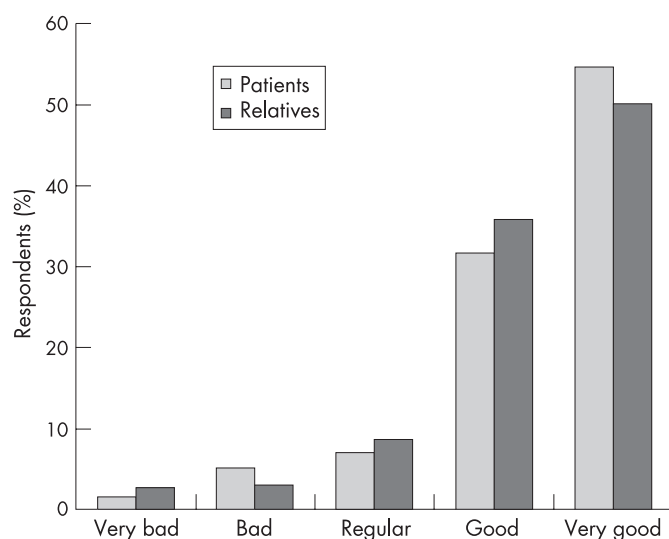
Rockwood<sup>12</sup> pointed out that many frail elderly people (those who have multiple, interacting medical and social problems) can comprehend normally when they are not ill and when they live with structured routines in familiar environments; but when they fall ill and go to hospital, their capacity may quickly be compromised, even in the absence of frank delirium. This may be one of the reasons why the autonomy of elderly people is commonly ignored in the acute care hospital setting. In our opinion, only if the patient demonstrates an incapacity to make decisions should the relatives be given information or asked for consent to treatment. In the UK, the consent and decisions of close relatives are considered desirable but have no legal force.<sup>11</sup>

It is clear that in a situation in which family members are integral to the care of the patient, it may be morally and practically indefensible to expect them to continue their care without necessary information,<sup>4</sup> and furthermore, some patients, especially if elderly, may prefer to delegate decision-making responsibilities to family members or the doctor.<sup>13 14</sup> However, we believe that such a situation can justify neither the indiscriminate disclosure of information nor the failure to provide it to the patient. Sayers and Bethell<sup>15</sup> present case reports concerning elderly patients with cardiac problems, in which there was great tension between doctors, patients and relatives, where medical interests, individual interests and family interests all conflicted.

Ruhnke *et al*<sup>10</sup> compared the attitudes towards ethical decision-making and autonomy issues in various clinical scenarios among physicians and patients in Japan and the United States and observed that Japanese physicians and patients relied more on the family's and the physician's

**Table 3** Information given to patients about the various stages of care and other information about their illness

Information	Age range (years), %			
	65-70	71-75	76-80	>80
Diagnosis	73.5	64.4	57.4	48.4
Complementary tests	69.9	69.4	61.7	48.4
Progress of illness	81.6	79.5	63.8	51.6
Treatment	60.3	57.1	53.2	29
Informed consent requested for complementary tests	57.1	56.2	40.4	35.5
Use of understandable language	38.1	26.2	23.8	11.9



**Figure 1** Patients' and their relatives' overall evaluation of care received

authority and placed less emphasis on the patient's autonomy, a finding similar to ours. The cultural context seem to shape the relationship between the patient, the physician and the patient's family in medical decision-making.

In our study, another important detail was the positive evaluation of the information received by patients despite the feeling that the information had been inadequate or even lacking in a substantial number of cases. Regarding the awareness of diagnosis, most of the almost two-thirds who were told the diagnosis understood it, but the finding that 32% of them "had doubts that they had not communicated to the doctor" reflects an understandable deficiency in the dialogue between doctor and patient. There are many reasons for these remaining doubts in patients' minds that do not imply that the doctor was at fault. This apparent contradiction between information received and satisfaction with it may be explained by the inadequate transmission of information to the elderly and the inability of some patients to assimilate what information they receive. We agree with Ghrea *et al*<sup>16</sup> that there is a gap between what doctors say (or think they say) and what patients understand. Doctors must become aware that patients may understand very little of their explanations.

There is a large difference in ages between patients and relatives—39% of patients were over 76, and 65% of relatives were under 65. Although this was expected, it tends to underline the likelihood that the relatives will understand information better than the patients. There is also a large difference in educational background of the elderly patients and their relatives: the patients had a limited education and

may not have understood all alternatives to, or all the major risks of, a proposed treatment—a factor that would influence both the doctor's motivation to supply information and the patient's ability to understand it. This difference may well account for the low percentage of patients over 70 who understood "informed consent". However, they may still have had enough overall understanding to make their own decisions.<sup>17</sup>

In such situations, it seems reasonable to try to ensure that the patient understands the nature of the medical intervention being offered and its risks and benefits; doing this may require, among other measures, the use of large print and clear wording on forms, and patience on the part of whoever is explaining.<sup>11</sup>

Information was provided in a high percentage of cases, but the main problem seems to be that it was unsuitable and not geared to the requirement to obtain valid consent. It also seems that the important point is not necessarily the information content but rather the quality of the human relationship enabling information transfer.<sup>16</sup>

Unnecessarily protecting patients whose mental capacities are intact, withholding certain information, and offering such information to relatives or others, thus not enabling the elderly patients to freely choose—all this may be an injustice. In accordance with the principle of autonomy, the best course would be to ask capable patients from the very outset and during the course of the illness to what extent they wish to receive information, take decisions and share information with others.<sup>18</sup> It is wrong for the doctor to adopt a passive or negative posture with respect to the provision of information. The problem seems to be that many doctors are unaware of the importance and extent of the information they should offer the patient.

It should be emphasised that the quality of medical care is defined by the outcome of medical-surgical activity and also by the information that the doctor provides. This is underlined by the fact that the patients and relatives expressing the highest regard for the care provided were those who thought they had received suitable information.

## CONCLUSIONS

Providing suitable and understandable information is a key element in the process of obtaining informed consent.<sup>19</sup> Obstacles in this process may be the doctor's reluctance to provide such information, with lack of time often cited as the reason.<sup>20</sup> However, an excessive workload, the withholding of information for objective reasons or a reluctance to provide information based on past professional habits cannot justify the scant or badly presented information offered to elderly patients. Hospital care can be improved only if health professionals adopt a more positive attitude to the process of providing information. We consider that both undergraduate and postgraduate courses should include communication techniques and knowledge of

**Table 4** Assessment of information received by patients and relatives who thought the quality of care received was "very good"

Question about information	Patients		Relatives	
	%	Probability*	%	Probability
Received information about diagnosis	72.9	<0.001	94.9	0.005
Understood the information well	85	<0.001	96.9	0.002
Used understandable language	77.6	<0.001	89.8	0.015
Received information about complementary tests	69.2	<0.001	87.8	0.006
Were asked for consent to carry out complementary tests	60.8	0.002	80.6	0.011
Received information on approximate duration of hospitalisation	64.2	0.022	61.5	0.003
Received information about treatment	63.6	0.003	70.4	0.03
Received information about progress of illness	90.7	<0.001	89.8	0.006

\*Pearson's  $\chi^2$  test.



patients' rights. In Spain, at the moment such courses emphasise the medical aspects and overlook the patient–doctor relationship.

Cultural aspects, too, are important, and family members frequently pressure doctors to prevent elderly patients from knowing the extent of their illness. It would therefore seem that an information campaign directed at the general public concerning patients' rights might be a good idea.

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